

Treatment

Treatments may include a wide variety of medications, nerve blocks, physical therapy, and psychological support for people with CRPS/RSD as well as for friends and family. Occasionally, surgical procedures are needed to control pain and abnormal nervous system responses. Treatment is individualized. Each patient should have a treatment plan that includes pain control, psychological support, and physical and occupational therapy.

If you think you have CRPS/RSD

If you have an injury that isn't healing as it should - if the pain or swelling is more severe than you expect for such an injury . . .

- Ask your doctor if this could be CRPS/RSD
- Make sure that you are getting treatment for the pain
- Try to keep the affected area moving
- Get another medical opinion if you feel that your physician isn't taking your complaints seriously.

Is there a cure?

No, but there is hope! Advances in research on pain and CRPS/RSD have helped find some new and effective treatments. More money and more research is needed to achieve the goals of understanding the causes of CRPS/RSD, finding

effective treatments for those living with CRPS/RSD, and preventing the development of CRPS/RSD after injury and tissue damage.

Reflex Sympathetic Dystrophy Syndrome Association of America (RSDSA) promotes public and professional awareness of CRPS/RSD. It educates those afflicted with the syndrome, their families, friends, insurance companies, healthcare providers, and others. RSDSA encourages those with CRPS/RSD to offer emotional support to others through affiliated support groups. RSDSA is committed to raising funds for research to find the causes and cures for CRPS/RSD.

For more information on CRPS/RSD, joining RSDSA, or making a donation, please contact our office or visit our website.

RSDSA

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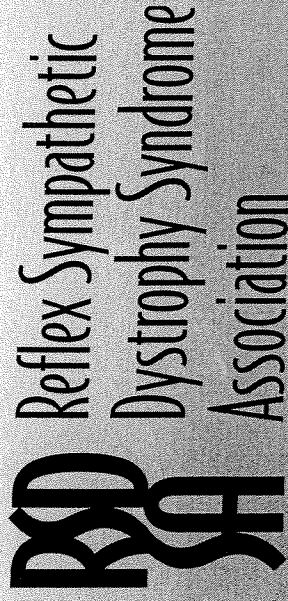
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Raising awareness of Complex Regional Pain Syndrome (CRPS) and Reflex Sympathetic Dystrophy (RSD) since 1984.



Recognizing,
Understanding, and
Treating CRPS/RSD

A potentially disabling,
chronic neurologic syndrome

also known as:

CRPS

RSD

www.rsds.org

What is Reflex Sympathetic Dystrophy Syndrome (CRPS/RSD)?

Complex Regional Pain Syndrome (CRPS), also called Reflex Sympathetic Dystrophy Syndrome (RSD) is a chronic neurological disease affecting an estimated 1.5 to more than 6 million Americans.

CRPS/RSD is a malfunction of part of the nervous system and the immune system as they respond to tissue damage from trauma, such as an accidental injury or medical procedure. Even a minor injury, such as a sprain or deep bruise, might trigger CRPS/RSD causing nerves to misfire, sending constant pain signals to the brain.

The term Complex Regional Pain Syndrome (CRPS) was adopted by the International Association for the Study of Pain to define two kinds of CRPS.

CRPS Type I (RSD) is characterized by

- The presence of an initiating event or injury, such as a sprain or fracture
- Continuing pain, including allodynia (pain resulting from a stimulus that normally does not cause pain, such as the touch of clothing or a light breeze); the pain is out of proportion to that associated with the original injury
- Evidence at some time of edema (swelling), changes in skin blood flow, skin color changes, skin temperature

changes greater than 1° C or abnormal sweating in the region of pain

- This diagnosis is excluded by the existence of conditions that would otherwise account for the degree of pain and dysfunction

CRPS Type II (Causalgia) is characterized by

- The presence of continuing pain including allodynia (pain resulting from a stimulus that normally does not cause pain, like the touch of clothing or a light breeze); the pain is out of proportion to that associated with the original injury; or hyperalgesia (heightened sensitivity to painful stimulation) after an identifiable nerve injury, not necessarily limited to the distribution of the injured nerve
- This diagnosis is excluded by the existence of conditions that would otherwise account for the degree of pain and dysfunction.

Symptoms of both (any combination)

- Pain: constant, moderate to severe
- Muscle spasm, loss of motion and use of the affected area
- Swelling that may come and go
- Skin Changes: Color, dryness, excessive sweating, excessive or decreased hair growth, changes in the nails

- Circulatory changes: cold or hot in the affected areas
- Insomnia and depression due to the other symptoms and life changes

Who can get CRPS/RSD?

Anybody! Anyone can get CRPS/RSD at any age, but studies show that it is more common in people between the ages of 25 and 55, and is more frequently seen in women than in men. It used to be considered rare in children, but there has been a recent increase in the number of cases among adolescents and young adults.

CRPS/RSD is a physical disease

CRPS/RSD is a physical disease. The symptoms may be caused by conditions that are not easily seen, prompting others to say, "But you look so well."

Diagnosis

A physician must make a clinical diagnosis of CRPS/RSD using a patient history, a thorough examination, and the results of numerous tests. There is no single test for CRPS/RSD.

Early diagnosis and treatment with pain control, physical therapy, and counseling offer the highest probability of remission from CRPS/RSD.

Birthdays

• Because of his background, this black-hatted singer really should know how to go to jail for country hits. F2 tells you who celebrates No. 28 today.



• Folk singer: Judy Collins, 66
• Film director: John Woo, 59
• Singer: Rita Coolidge, 61

Sunday Today

SECTION F
The Flint Journal

ENTERTAINMENT
THURSDAY

TELEVISION
FRIDAY

RELIGION
SATURDAY

FEATURES
Sunday, May 1, 2005

HEALTH & FITNESS
MONDAY

FOOD
TUESDAY

FEATURES
WEDNESDAY

No relief in sight

What could be worse than having a disease that causes excruciating pain, and that most doctors don't know how to diagnose or treat? Reflex Sympathetic Dystrophy (RSD) is a little-known neurological disorder that causes severe, spreading pain. At its worst, it confines previously active children and adults to beds or wheelchairs.



▲ Allison Switalski, 12, was in the hospital for treatment for pain in March 2004.

Paula Abdul disease could help battle neurological disorder

By Rose Mary Reiz
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American Idol judge Paula Abdul's recent announcement that she suffers from a little-known neurological disorder could be a mixed blessing for those battling the same disease.

"I'm already calling it 'the Paula Abdul disease,'" said Cynthia Toussaint of California, a former ballerina who suffers from Reflex Sympathetic Dystrophy (RSD), a chronic disorder that causes severe, debilitating pain. (See story at left).



Paula Abdul

"She could make RSD a household name."

Abdul, 42, has said she was diagnosed with RSD in November after a

► Abdul, F2

Some answers

What is RSD?

Reflex Sympathetic Dystrophy (RSD), also called Complex Regional Pain Syndrome, is a neurological disease in which nerves misfire and send constant pain signals to the brain. The disorder is unique in that it simultaneously affects the nerves, skin, muscles, blood vessels and bones.

What causes it?

The cause always can't be traced, but RSD often follows a traumatic event, like a sprain, fall, accident or medical procedure. The severe pain of RSD is out of proportion to the injury that triggered it and lasts long after the injury has healed. The original injury may happen weeks, months or even years before a correct diagnosis is made.

What are the symptoms?

In addition to constant, severe burning pain, which can spread to different parts of the body, symptoms include skin sensitivity, swelling, excessive sweating, abnormal skin color, skin temperature changes, muscle spasm, limited movement, vision problems and vision loss. Eventually, joints become stiff from disuse, and skin, muscles and bones can atrophy. Sometimes, patients are confined to beds or wheelchairs.

Patients do not always get every symptom, which makes RSD difficult to diagnose.

How painful is RSD?

It is considered the most painful

► Answers, F2



The Flint Journal • Lisa DeJong

▲ Allison sports a "Fragile: Handle With Care" T-shirt as she giggles with her mom, Dorothy Switalski. The T-shirt has taken on a deeper meaning as Allison and her family struggle to understand her condition. Allison has a little-known, and little-understood, neurological condition called Reflex Sympathetic Dystrophy (RSD) that causes nerves to misfire and send constant pain signals to the brain.

Montrose Township girl battles attack by painful 'monster'

Most doctors are unfamiliar with RSD, so people with the condition sometimes wait years before it is diagnosed properly. In the meantime, their lives ebb away. They often are dismissed by family members, friends and doctors as "attention seekers." Many RSD sufferers have committed suicide while waiting for appropriate treatment.

Today and tomorrow, we tell the story of a local 12-year-old girl and her battle with RSD.

By Rose Mary Reiz
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Allison Switalski knows that there is only one thing worse than being in constant pain: not being believed.

"The worst part was when some of the kids at school started an 'Alli's Faking It' club," said Allison, 12, of Montrose Township.

"It hurt my feelings, but I can understand why they did it. One day I'd be on crutches, then I'd be walking fine, then I'd be on crutches again. They couldn't figure out what was wrong with me."

For a long time, neither could anyone else. Doctors couldn't understand how a



The Flint Journal • Lisa DeJong

▲ Allison drew this picture. Her RSD started with a twisted ankle, but even as the ankle began to heal, Allison's pain skyrocketed.

simple, twisted ankle resulted in pain so severe that Allison once had to crawl from her sixth-grade classroom to the school office to call her mom.

They couldn't explain why the weight of cloth on her skin was so excruciating that her parents had to cut the backs out of her T-shirts. Or why, when riding in a car, a bump in the road made her moan and cry.

Allison's problems began in the summer of 2003. An outgoing, competitive athlete, she twisted her left ankle while playing basketball. Soon, her ankle was black, blue and swollen to twice its normal size. Allison, irritated at being sidelined, insisted she was fine. X-rays confirmed that no bones were broken.

She should have been back to normal in no time. But the next month, when she went to the first soccer practice of the season, the pain was back with a vengeance. She hobbled off the field.

She attended the next three practices with the same results. Maybe she was trying to do too much, her parents thought. Maybe she should choose between soccer and basketball.

Allison chose basketball. At the first practice, pain again shot through her ankle. Allison staggered off the court and was on crutches for the next three days.

The family pediatrician prescribed ibuprofen and ice. The pain worsened. An orthopedic specialist prescribed a leg brace and physical therapy. The swelling subsided, but the pain persisted. An MRI revealed nothing that should have caused such pain.

When Allison began having pain and popping sensations in her other ankle, confused doctors suspected arthritis. A pediatric rheumatologist examined her, found no signs of arthritis and sent her home. Her mother, Dorothy, balked.

"I said, 'Wait a minute. I can't take her home without getting some help. Something's wrong with her. She can't even walk without crutches.'"

Dorothy almost could feel the doctor resist rolling his eyes. She was beginning to know the frustration of being dismissed as a "difficult" parent. In an obvi-

► Battles, F2

INSIDE

Columnists, F2

HELLER
ANDREW HELLER

BRISSETTE-MATA
BRENDA BRISSETTE-MATA

Books, F3

▲ "Paddy Whacked" is an awesome work of scholarship — and an outrageously enjoyable read.

Entertainment, F5

▲ Racing movie about more than machines.



Tim McGraw, son of a former baseball player, is 38.

All she wants is another WHAT?

The lovely yet formidable Marcia disappeared for half an hour to the neighbor's house across the street.

"What gives?" I thought. "We barely know those people."

She came back with a look on her face. And not just any look. But "that" look.

I've seen it before. It's the "I-

have-just-spent-the-last-half-hour-cradling-a-newborn-and-maybe-it's-not-too-late-for-me-to-have-just-one-more" look.

Oh my.

"You should have SEEEEN it," she squealed.

Andrew Heller

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"You should have SMELLLLLLL it," she sighed.

No thank you, I said. I know what babies look like. They all look like Winston Churchill. And I certainly know

what they smell like. I changed many a diaper in my day.

"Not that smell, dummy," she said. "The good one. The baby smell. All baby powdery and sweet."

I know that one, too. It's indeed attractive. That's one of the ways the evil little bug-gers hook you. They smell good and act cute, and after you haven't had one for a while, you start to forget how much work they are and how you swore you'd never, ever have one again.

Luckily for me, I can't and won't have another baby for the following reasons:

1) Marcia had me what she calls "fixed" and what I call "most definitely broken."

I consider it a dark day for humanity.

2) I have a very good memory.

We have three children, so I distinctly remember not sleeping for 10 years straight.

I also remember not owning a shirt that didn't have up stains on it.

I remember spending half of our disposable income on disposable diapers. I also remember our one-week trial with cloth diapers, and how the vapors from the diaper pail caused a block-wide evacuation.

I remember Marcia developing huge biceps from carting a car seat everywhere. (She still can crack walnuts with them to this day. Ask her.)

I remember the death of something we used to call our "social life." (We still

don't have one, only now it's because of the tragic, worldwide shortage of baby-sitters.)

I remember the constant worry. I remember the incessant doctor's appointments. I remember forgetting how to have an adult conversation. I remember saying to a buddy once, "Hang on, I have to go pee-pee."

I remember wondering whether it wouldn't be easier to just buy amoxicillin (aka "the pink stuff") in gallon-sized drums.

I remember colic. Annie had colic. I remember thinking I wouldn't survive it. To this day, I'm not entirely sure that all of my brain cells did.

I definitely remember projectile vomiting.

I also remember first

smiles, first teeth, first words, first steps.

I remember cooing and rocking and that amazing "I did that!" feeling.

I remember how babies make you forget yourself, which is nice.

I remember how babies instantly and repeatedly remind you that the world is a much nicer and more hopeful place than you used to think.

I remember tiny faces diving into first birthday cakes.

I remember.

Aw, jeez. I definitely gotta keep her away from the neighbors.

Listen to the Come Heller High Water radio show, with co-host Norma Hall, weekday mornings from 7-9 on WFMT-AM (1470).

There she isn't could be a first

"There she is, Miss America. There she is, your ideal."

In 1920, the 19th amendment gave women the right to vote, and in 1921, a bunch of men in Atlantic City decided to conduct a beauty contest.

It's been 84 years since the first Miss America pageant, a long and bumpy road.

"The dream of a million girls who are more than pretty, can come true in Atlantic City."

The '20s were roaring and so were the women. Maybe a

little too much. In 1929, religious groups and women's clubs protested the "loose morals" of the women and the pageant was shut down.

In 1932, aiming for a cleaner image, the organization hired director Lenora Slaughter, who turned Miss America into a patriotic symbol. She also raised \$5,000 for the contest's first scholarship in 1944.

Scholarship or not, it still was about beauty. There were no ugly women vying for that money.

Slaughter, offended by the phrase "bathing suit" changed it to "swimsuit" and said winners no longer could walk the runway in the skimpy ensemble and instead would be crowned wearing an evening gown.

Brenda Brissette Mata

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"With so many beauties, she took the town by storm. With her all-American face and form."

But only a white, all-American form.

The race qualification was part of the 1948 pageant contract, but the stipulation caused less controversy than Yolande Betbeze's refusal to appear in public in a swimsuit. Miss America 1951, Betbeze's action led to Catalina Swim-

wear, a major pageant backer, pulling its sponsorship. The company went on to create two new beauty contests, Miss USA and Miss Universe.

"There she is, Miss America. There she is, your ideal..."

Since 1954, viewers tuned in their televisions to watch Bert Parks sing those words as the newly crowned young woman strolled down the runway.

At the peak of the contests, more than 80 million people watched in one night.

Slowly, the world began to change.

In 1968, feminists protested the pageant and a Miss Black America contest was held on the same day. Pepsi withdrew sponsorship because Miss America did not represent the changing values of American society.

In 1970, rules changed and the first black contestant walked the runway.

It wasn't until Rebecca King, Miss America 1974, actually used the scholarship money for professional education. She became a lawyer.

"Walking on air she is ... the fairest of the fair, she is ..."

The first roll in: Vanessa Williams, the first black woman crowned in 1984; Kaye Lani Rae Rafko, the

first to dedicate her reign to a social issue in 1988; Heather Whitestone, the first with a physical handicap in 1995; the first bikini in 1997 (the last bikini in 1999); and the first Asian Miss America, Angela Perez Baraquio, in 2000.

Unless someone wants to be the first ugly Miss America, there seemed to be no frontiers left. Then, in October, ABC announced it would no longer carry the pageant since only 9 million people watched. That's about the same number of people who watch "Judging Amy" on Tuesday nights.

There could be one first left — the first year without a pageant.

"There she goes, Miss America."

Abdul: Disease could help battle with disorder

series of accidents triggered severe pain. The disorder is characterized by unremitting pain following an injury.

Added to the physical pain of RSD is the emotional pain of not being believed. Most doctors are unfamiliar with the disorder and Toussaint, like many RSD patients, was dismissed for years by physicians who told

her the problem was "all in your head."

Improperly diagnosed and treated, the condition can cause permanent, irreversible damage. In Toussaint's case, she lost her career and her mobility to the disease.

"I spent nearly a decade of my life bedridden, writhing in pain, thinking about suicide," said Toussaint, who is confined to a wheelchair. "I still have days when I go to get through the next minute."

Toussaint's experience

with RSD is more typical than that of Abdul, who says she finally is pain-free after treatment.

"Four out of five people with RSD don't ever return to their former activities," said Jim Broatch, executive director of the Reflex Sympathetic Dystrophy Syndrome Association.

Broatch is hopeful that Abdul's announcement will bring attention to what he calls "our little-known, under-diagnosed syndrome." But both he and Toussaint are concerned

that the public will see how well Abdul is doing and discount the severity of the disorder.

"I hope her case doesn't make other people with RSD feel like failures because they're not cured," Toussaint said.

Perhaps Abdul's case shows what can result when a patient is believed by doctors and gets excellent, early care, she added.

"Unfortunately, I'm the example of the dancer who was not believed and didn't get care in time."

Answers: What is RSD, how painful, etc.?

chronic pain disease that exists. It is ranked 42 out of a possible 50 points on the McGill pain index, a graph that attempts to measure and compare different types of pain. RSD pain ranks twice as high as that assigned to fractures, arthritis and cancer, 10 points above the pain of childbirth and roughly equal to the pain of amputation.

The pain of RSD often is described as burning, deep, aching, stabbing, crushing or cold. Something as simple as a light touch of clothing or a loud noise can increase the pain. Stress exacerbates symptoms. A drop in barometric pressure increases RSD pain for nearly three out of four patients. Humidity also tends to increase pain. For some patients, cold temperatures make the pain escalate; for others, heat is the culprit.

How many people have RSD?

No one knows for sure, but according to the best estimates, between 1.5 million and 7 million Americans suffer from RSD. The disease first was described during the American Civil War, when wounded soldiers would wrap their affected limbs in wet rags to "extinguish the fire."

Who gets RSD?

Women account for 75 percent of RSD patients. The disease strikes people of all ages, but 65 percent contract RSD during middle age. The disease used to be considered rare in children, but there has been a recent increase in the number of cases among adolescents and young adults. Girls are affected five times as often as boys. The incidents increase markedly just before puberty, and female dancers, gymnasts and competitive athletes comprise a high percentage of RSD patients.

Is there a test for RSD? No. It must be diagnosed clinically using a thorough patient history and physical examination.

What about RSD and depression?

RSD is a physical, not psychological, disease. However, insomnia and depression may result from other symptoms and life changes. Because persistent pain is invisible, many doctors, educators and employers assume people with RSD are exaggerating, seeking attention or malingering.

Most RSD patients were active and productive prior to the disease and do not enjoy the pain, social isolation or loss of independence, job, school or income.

Being misunderstood adds to depression in RSD patients. According to the American RSDHope group's national survey, more than 70 percent of RSD patients questioned considered themselves depressed. More than half of those surveyed said that they "seriously" thought about suicide as an escape from RSD pain.

Counseling, physical therapy and involvement with support and advocacy groups are ways some patients successfully battle depression.

Is there a cure for RSD?

There is no cure, and chances for a complete, symptom-free remission are low. The disease may subside for years and then recur with a new injury. But research is ongoing, and there is hope in the form of improved treatments, new medications and new uses for existing medications.

The younger the patient and the earlier the diagnosis, the better the chances for remission and, in a few cases, reversal.

How is RSD treated?

Because RSD is often misdiagnosed, it often is treated in ways that worsen the disease. For instance, applying ice or immobilizing the affected area can cause the pain to increase and spread. The "no pain, no gain" philosophy does not apply to RSD; forcing movement to the point of pain can worsen the condition.

Appropriate treatments are designed to decrease pain while increasing movement and may include medication, nerve blocks, physical therapy, electrical stimulation of nerve endings, implantable medication pumps and surgery to cut affected nerves. Treatment may include pain control, psychological support, physical, occupational or massage therapy.

Treatment needs to be highly individualized. The condition is difficult to treat, and what helps one patient may not help another.

Information provided by the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA), the American RSDHope Group, the National Institute of Neurological Disorders and Stroke and For Grace, a nonprofit organization devoted to raising public awareness of RSD. For more information, call For Grace at (818) 760-7635; RSDSA at (877) 662-7377, or visit the following Web sites: www.rsd.org, www.forgrace.org, www.rsdhope.org, www.ninds.nih.gov.

Battles: Montrose Twp. girl fights the 'monster'

ous effort to appease her, the doctor prescribed more physical therapy.

Although pain was no fun, Allison still was a happy, easy-going girl. She still enjoyed artwork. She still loved filling her pink bed-room with as many Piglet toys and figurines as she could find.

As the youngest of three children and the only daughter, she didn't lack for attention. Neither was she a wimp. She could hold her own when sparring with her two older brothers, Matt, 19, and Andy, 16. While her symptoms puzzled her, she was confident that, between her parents and the doctors, someone would figure out what was wrong and fix it.

In the weeks that followed, Allison's elbow began to make popping noises and hurt. The pain spread to her shoulder. She still often needed crutches and began having headaches. She sometimes needed Tylenol with codeine just to get to sleep.

Seven months after Allison first twisted her ankle, she rolled it again while walking to the front of the class to turn in a paper. The pain was ferocious. She hobbled back to her seat and waited until everyone else left, then hopped out on one leg.

By the time she got to her locker, the hallway had emptied of students. Now it was too much pain even to hop, she crawled on her hands and knees to the school office to call her mom.

The family doctor wrote a referral to a University of Michigan Hospital orthopedist. While waiting for the appointment date, Allison's symptoms multiplied. She began having stomachaches. Pain in her wrist became so severe she couldn't grasp a pencil. Both her knees



The Flint Journal • Lisa DeLong

▲ Now feeling better, Allison Switalski snuggles with her dog, Daizee, that was at her side throughout all the pain Allison endured over the past year.

ached.

Dorothy and Steve tried to maintain a positive attitude in front of their daughter. In private, they fretted and cried. Allison seemed under attack by some monster they couldn't name and didn't know how to fight. Her condition, physical and emotional, worried them sick.

"I noticed that she was starting to shut down a little," Steve said. "She still had that spark, and she was still saying things like, 'It's OK. I'll play soccer in the spring when I'm better.' But she was more quiet than usual."

Pain was consuming most of Allison's energy. What little she had left, she spent trying to stay upbeat in front of skeptical friends, teachers and doctors.

"Why do you get to stay home so much from school?" envious classmates asked.

How come sometimes you need crutches and sometimes you don't? "What's wrong with you, anyhow?"

One day, a teacher, frustrated with the amount of school Allison was missing, chided her, "You know, Alli, it's just as easy to be in pain in school as it is at home."

Doctors hinted that Allison might be exaggerating symptoms to get attention and that her parents were "enabling her."

"I was furious," Dorothy said. "But I kept my cool because I needed their help. All I said was, 'How do you enable someone not to be able to walk?'"

Nine months after Allison's original injury, the pain in her left ankle still was constant. She also had pain in both knees, her right elbow and left wrist. In between bone scans, X-rays, physical therapy and a smorgasbord of pain medications, Allison tried to go to school. Sometimes she made it through the first hour; only to return home with an excruciating headache or leg pain.

Dorothy and Steve, a test mechanic at General Motors, held their breath each day until they knew how Allison was doing. On a good day, she got up and went to school. On a bad day, she could only lie in bed, moaning.

Once she described the pain in her left ankle as "bombs exploding." On some days, "What hurts?" she could only cry and mumble, "Everything."

She got to the point where the pain was so bad she couldn't even cry," her mom said. "There's a point where the pain reaches a level that's beyond tears, where you don't have the energy to cry."

Allison's parents felt heartbroken and helpless.

"It's a terrible feeling when there's nothing you can do or say to make it better," Steve said. "When she was in a lot of pain, all we could do was try to distract her by putting a movie on or bringing the dog in."

Allison's brothers no longer teased their sister but instead carried an extra television set to her room for her to watch from bed. When she was in so much pain that she had to crawl up the stairs to her bedroom, the family dog, Daizee, waited patiently at the top.

Classmates, homework and sports seemed far away. Dorothy, a school board member and normally a stickler for homework, no longer cared whether her daughter opened a textbook.

"That's really something coming from me," Dorothy said. "But it was all we could do just to survive. All I could concentrate or read. It took all she had just to be."

Survival meant lots of prayers — that Allison would be healed, that the next doctor would have an answer, that the next day would be better than the last.

And the prayers of any parent whose child is in pain. "You just wish it was you instead of her," Dorothy said. Allison, bleary from pain and medicine, prayed, too.

"My prayer was just, 'Help me.'"

Help finally came from a doctor in Ann Arbor. While Allison was getting dressed after yet another unproductive examination, the doctor noticed her wince in pain just from touching her sock to her foot.

The doctor then asked a question that would change Allison's life.

"Have you ever heard of RSD?"

Tomorrow: Allison finally gets a diagnosis, but her condition gets worse before it gets better.



Andrew Heller

Let's stop pretending Flint's cool

I agree that Flint has an image problem.

I emphatically disagree, for perhaps the 100th time, that the solution to it is a public relations campaign.

That suggestion was made last week at an International Institute forum about why the city isn't perceived to be "cool" by young people despite having 25,000 students attending college within its boundaries.

The idea came from a Kettering University dean, who I'm sure had the best of intentions. Unfortunately, she's guilty of the same misstep many have made before her in this overanalyzed town, and that is putting the flack before the horse.

(Flack, in case you don't know, is a slang term for a public relations person.)

Flint's lack of coolness isn't because the much-salivated-after 18- to 34-year-old demographic doesn't know about all the good things Flint has to offer. It's because 18- to 34-year-olds, like the rest of us, have eyes in their skulls.

Those eyes see: crime, violence, poverty, decay, a downtown nearly devoid of retail and nightlife, empty factories, a lack of ability by City Hall to improve things.

You can't fool people. A public relations campaign won't change any of those realities, any more than the false, honey storefronts slapped on the empty buildings along Saginaw Street last decade changed the reality of downtown.

Remember that old saying, "You can put lipstick on a pig, but it's still a pig?"

That's what a PR campaign for Flint would be like. (And no, I'm not calling Flint a pig. It's just an analogy. OK? I live here. I like it here. Save your letters.)

A PR firm would slap cute phrases on the city, maybe come up with a bouncy jingle ("Flint is cool! Flint rules! Flint doesn't drool!") and remind us about things like our wonderful hospitals and the Cultural Center.

And in the end, it'll mean nothing. Young people will see through it in a second.

Like I said, they're not dumb. They'll begin to think Flint is a cool, hip, exciting place when it's safe, prosperous and bustling, same as any other demographic.

We've fallen into that trap before of thinking that if we say something long enough people will start believing it. Flint's "image" has been studied to death.

Study, in many instances, is the enemy of action. Flint needs deeds, not words. We need to encourage our colleges to build dorms so most of their 25,000 co-eds don't bolt to the suburbs at night. We need to improve the city's schools so young families likewise don't flee and so kids grow into contributing adults. We need to cut crime, continue drawing business downtown, clean things up, insist on better leadership and so on.

We do those things, Flint won't have to pretend it's cool.

It'll be cool.

Tomorrow



A month of meals

► There are classes for this, you know.

Birthdays

• Wrestling star "The Rock" (real name, Dwayne Johnson) has a signature facial gesture called the "people's eyebrow," which he might raise today to celebrate his 33rd birthday



• Figure skater: Sarah Hughes, 20
• Actress: Christine Baranski, 53
• Singer: Lesley Gore, 59

What's Inside

► "24" is packed with tons of action tonight, 8 p.m.
► "Chicken Soup for the Soul," 8 p.m.
► Breast enlargement in



Today

SECTION D
The Flint Journal

TELEVISION RELIGION FEATURES HEALTH & FITNESS FOOD FEATURES ENTERTAINMENT

FRIDAY SATURDAY SUNDAY

Monday, May 2, 2005

TUESDAY WEDNESDAY THURSDAY

Past the pain

12-year-old has tough trip from twisted ankle to relief



▲ Allison Switalski, 12, (far right) teases her best friend, Abby Stark, 12, (far left) about smiling before they go on stage in "Guys and Dolls Jr." Allison has a little known, and little understood, neurological condition called RSD.

The second of a two-day series

By Rose Mary Reiz
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The nightmare began when Allison Switalski, an outgoing, athletic 10-year-old from Montrose Township, twisted her ankle during basketball practice.

In the months that followed, what should have been a minor, half-forgotten injury became a catastrophe. The pain in Allison's ankle worsened and spread, first to her other leg, then to her knees, elbow, shoulder, arm and hand. She had headaches, dizziness and blurred vision.

Unable to put weight on her legs, she had to crawl on her hands and knees up the stairs to her bedroom. A breeze, or the touch of clothing on her skin, could make her cry in pain. She was exhausted but couldn't sleep.

Normally an enthusiastic student, Allison missed a lot of school. Her classmates couldn't understand her frequent absences. Suspicious that she was exaggerating her symptoms to get attention, some withdrew.

"Some kids were really good friends before this, and then they weren't anymore," Allison said.

Allison's parents, Dorothy and Steve, were desperate to get help for their daughter. The squares on their calendar, once filled with social, school and athletic events, were now scribbled black with doctor's appointments.

Most physicians were well-meaning. All were baffled. A sprained ankle couldn't have caused this much



▲ Allison and her mother, Dorothy, went to Lansing to try and make legislators more familiar with Reflex Sympathetic Dystrophy. Allison has a little known neurological condition that causes nerves to misfire and send constant pain signals to the brain.

pain. X-rays, bone scans and blood tests ruled out arthritis and every other condition they could think of. Pain medication and physical therapy weren't helping.

Some doctors told Allison that she needed to "be patient and wait for the pain to go away." Others suggested that the pain "was in her head." One nurse was

► Allison, D2

and its companions: anger, frustration, worry, grief and guilt.

"Thinking back now, it makes us very angry that doctors didn't know the signs

► Monster, D2

What could be worse than having a disease that causes excruciating pain, and that most doctors don't know how to diagnose or treat? Reflex Sympathetic Dystrophy (RSD) is a little-known neurological disorder that causes severe, spreading pain. At its worst, it confines previously active children and adults to beds or wheelchairs.



▲ Allison looks up at portraits of former Michigan political figures as local Rep. John Gleason gives her a tour inside the Michigan State Capitol in Lansing.

Battling the 'monster'

By Rose Mary Reiz
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Doctors call it Reflex Sympathetic Dystrophy. Or RSD. Or Complex Regional Pain Syndrome.

Patients have a better name for it: The Monster.

"We all end up calling it that," said Dorothy Switalski, whose 12-year-old daughter, Allison, has battled RSD for two years. (See story at left).

"It is a monster. It inflicts so much pain, and it's so hard to stop. It just keeps coming and coming."

RSD is a little-known neurological disease in which nerves misfire and send constant pain signals to the brain.

The pain of RSD is considered the most severe of any chronic pain condition. Even the breeze from a ceiling fan or the light touch of clothing can cause excruciating pain.

The monster is almost as hard to explain as it is to endure.

"You get so tired of trying to explain it to people," Dorothy said. "Most of our friends know that there's something wrong with Alli, but they don't really understand what it is. And I don't expect them to. It's a hard disease to figure out."

There are a few people who require no explanation: other RSD parents.

"I couldn't have survived the past two years if I didn't have the support of other people going through this," Dorothy said. "They have saved my sanity."

Almost every day, in between family activities, appointments and assignments as a professional photographer, Dorothy sits at her computer to participate in a nationwide, online support group. There, parents of children with RSD join forces to battle the monster



▲ Hoots the Owl explains the benefits of healthy fruits to Cookie Monster on "Sesame Street."

Fruits, veggies become the main source on 'Sesame Street'

By Jennifer Frey
The Washington Post

There is a panic in the land, and it started on "Sesame Street."

The rumors, they are rampant. Taken together, in dark tones, and one could fear that the beloved boulevard is rapidly transforming into the Avenue of the Politically Correct Puppetariat.

Elmo and Zoe are on an exercise routine. Singing vegetables and talking fruit have invaded the neighborhood. Miles has a new song. It is

about broccoli.

And, darkest of all, Cookie Monster has been stripped of his piles of quickly and loudly consumed chocolate-chip cookies.

From California to Australia, from New York to Oregon, fears have arisen about the sanctity of "Sesame Street," the children's show that just started its 36th season. The Los Angeles Times editorialized on the crisis, a staffer at the South Australia Sunday Mail declared herself "rocked to my foundations" by Cookie Monster's transformation, and The

Associated Press bemoaned Cookie's new circumstances in a missive sent across the land. The blue fuzzball even wound up on this week's "Hit List" in Entertainment Weekly.

"Cookie Monster to Cut Down on Sugary Treats" reads the EW item, followed by a rant that begins with the word "Sellout!"

Rosemarie Truglio, vice president of education and research for Sesame Workshop, sighs when asked about all the fuss.

► Sesame, D2

Allison: It's tough trip from twisted ankle to relief

convicted that Allison was having an emotional reaction to the World Trade Center bombing.

"The physical pain of RSD is excruciating," Dorthy said. "But the pain of not being believed is almost as bad."

Eight months after Allison twisted her ankle, an orthopedist in Ann Arbor watched her wince in pain while putting on her sock after an examination.

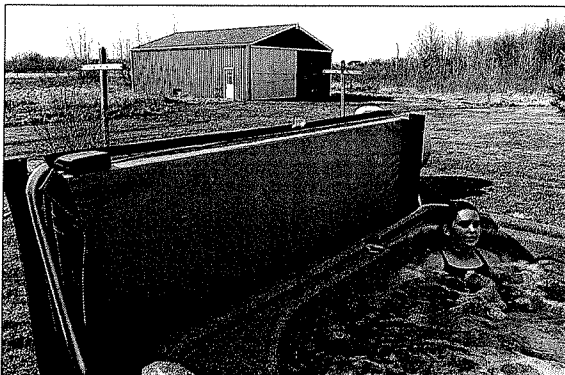
"Have you ever heard of RSD?" the doctor asked. She explained what she knew about Reflex Sympathetic Dystrophy, a chronic pain disorder.

"She didn't know too much about it, but she was the first person to correctly identify what we were dealing with," Dorthy said. "She will always be my hero."

At home, Dorthy logged on to her computer to learn all she could. Everything she discovered convinced her that Allison did have RSD, a little-known and often misdiagnosed neurological condition that causes nerves to misfire and send constant pain signals to the brain.

Through organizations like the Reflex Sympathetic Dystrophy Syndrome Association, Dorthy learned that RSD often follows a traumatic event. The disease is not fatal, but it is considered the worst of any chronic pain disorder.

There is no cure. Treated early, usually with medication and nerve blocks, remission is possible. Without proper treatment, RSD renders most patients disabled. There is no single test to diagnose RSD. Most doctors never have encountered it, and many are skeptical that it even exists.



▲ Allison Switalski, 12, tries to soothe the pain of a broken toe at her home in Montrose Township. Allison and her family were worried that this broken toe could turn into excruciating pain because of her disease. The hot tub seems to help alleviate some of her pain.

Allison was referred to a hospital in Detroit, where doctors agreed that she was suffering from a pain disorder but couldn't agree that it was RSD. They scheduled her for an epidural, or spinal pain block, and a catheter to deliver pain medication, to be followed by physical therapy.

Allison never got that far. After the epidural, she was in excruciating back pain. It didn't help that a tube connected to her back had been caught on a pole and jerked when she was moved to her bed. The procedure would have to be repeated, the doctor said.

"We couldn't believe they wanted to do it again with her in this much pain," Dorthy said. "Even touching a cotton ball to her skin sent her through the roof. Finally they told us, 'Well, go home

and think about it.'"

Allison was discouraged. Beyond discouraged, Dorthy and Steve started to drive their daughter home.

"On a scale of one to 10, if four is a bad toothache, then Alli's pain most of the time was a nine," her dad said. "During that period, it was a 15."

The drive home lasted 10 miles.

"Every time we went over a crack in the road, Alli was screaming in pain," her mother said. "We called the hospital and told them we were coming back."

Admitted to the emergency room, Allison was given morphine. Neither that nor anything else brought relief. The drugs caused her breathing and heart rate to drop dangerously low. She was given oxygen.

Every bump of her bed, every needle injection caused the pain to skyrocket. She could sleep for just moments at a time. By the 11th day, doctors admitted they had run out of ideas. They suggested Allison be taken to the Mayo Clinic, the Cleveland Clinic or Children's Hospital in Boston.

Allison was given prescriptions for more pain medication and sent home. By this time, her back pain was so great that even the weight of a T-shirt was unbearable. She couldn't walk or sit.

"We saw her go from crutches to a wheelchair to a reclining wheelchair," her mother said. "That was the lowest point. Seeing her lying in that wheelchair made me think she'd never get up again."

Allison's frantic parents

made an appointment for her at the Cleveland Clinic, where, almost a year to the date since her injury, doctors finally confirmed that she had RSD.

"It was the first time that doctors didn't question the pain levels she was having," Dorthy said. "It was the first time we got a definitive diagnosis from someone who knew about RSD and had real ideas on how to treat it."

Home again, this time on steroids and with an appointment for a nerve block, Allison began to improve. She progressed from a reclining wheelchair to a regular wheelchair to walking, a few hesitant steps at a time, on crutches.

Her biggest breakthrough came one Sunday morning while attending Mass with her parents. Allison usually was transferred from a wheelchair to a church pew, where she remained seated during the service.

"This time, when we stood during Mass, she stood next to me and tugged on my sleeve," Dorthy said.

Astonished, Dorthy turned to her daughter, who whispered two words her mother had almost given up on hearing: "No pain."

For a girl who had been long prayed for by family and friends, it was an appropriate setting for a breakthrough that has since led to remission. Almost two years after her fateful twisted ankle, Allison, 12, still struggles with blurred vision, stomach and back aches. But she often is pain-free.

One day, she fell while riding her bike. With blood running down her legs and her elbows scraped raw and studded with gravel, she happily proclaimed to her mom, "It's just normal pain!"

School sports still are off-limits, but Allison is a busy

seventh-grader who plays the cornet, is a member of her school's National Honor Society, drama club, student council and swim team.

Allison has lots of friends. The more her classmates and teachers learned about her condition, the more supportive they became, she said.

"One of my friends, when I had to crawl upstairs, would crawl right along with me," she said. "Another boy from school sent me an e-mail apologizing for not believing me when I was sick."

Allison takes medication three times a day, uses a hot tub for pain relief and has regular appointments with a Cleveland RSD specialist. Her prognosis is good. Unlike adults with RSD, children, once in remission, often remain pain-free.

When Allison was a little girl, someone asked her what she wanted to be when she grew up. Her off-the-wall answer, "a plumber," has been the source of family jokes for years.

Lately, she has other career plans.

"I would sort of like to be an RSD specialist," she said. "Allison's mom is all for it."

"We're not anti-doctor," she said. "We just want them to listen and learn more about RSD so that patients can get properly diagnosed."

In the meantime, Allison has become a vocal activist on behalf of RSD sufferers. She recently visited State Rep. John Gleason, D-Flushing, in Lansing to promote legislation that would increase public awareness and mandate education about RSD.

Her mother is not surprised at her daughter's activism.

"One of her former teachers told me, 'Don't underestimate the power of Alli.'"

"I never do. She's taught us all so much about life."

Monster: Battle involves anger, frustration

of RSD," wrote one mother whose daughter suffered classic symptoms for more than a year without being diagnosed, only to be told later that "it could have been treated if it had been caught early."

Another mother was angry with a doctor who insisted that "children don't get RSD," and that her son "was malingering to get attention."

Another expressed the common frustration of being patronized by doctors unfamiliar with the disorder.

"I was looked at as the mother who was trying to make my little girl into an invalid because I insisted on pain relief for my child."

One woman described an incident in which the assistant principal of her daughter's middle school took the girl's crutches away from her, saying that she was "faking" her sprained ankle.

Others expressed frustration with themselves for not being smarter, braver or having "superhuman powers."

"(Before RSD), I lived

under the impression that as a mother, I had the power to fix everything," one parent wrote. "I have had to come to terms with not being able to take care of every problem."

Another described the guilt of paying more attention to her ill child than her healthy ones. Still another admitted that she allowed an insistent doctor to inject her daughter's ankle with steroids in spite of her fear that the injection would cause an RSD flare-up.

"I let them do it," she wrote. "Sometimes as parents, we just feel that we should be fired from our jobs."

Along with frustrations and failures, parents share the relief of finally finding a doctor who understands, a program that helps, a medication that works, a procedure that brings relief.

One mother shared her experience with an emergency room physician's assistant, a compassionate, humorous man who was the first to suggest her daughter might have RSD. Instead of sending the girl home as his boss had ordered, he called several specialists and "sent us off with a referral and kind

words, which I feel saved my daughter's life," the mother wrote.

Another mom shared the wonderful treatment her daughter received at a children's hospital, calling the staff "a Godsend. The disease is treated as a family disease and with a ton of humor. In fact, they say RSD stands for Really Stupid Disease. They have offered us unending support and guidance."

For some, there has been the relief of remission and recovery. But those familiar with the RSD monster know its habit to retreat and return.

"For some time to come, if not forever, you must be ever mindful that RSD is just hiding around the corner," a grandparent cautioned. "It is a sad fact of life that this is a condition there is no cure for."

A mother whose adult daughter has the disease wrote, "My daughter, Julia, though in 'remission' since 1991, has just in the past year, or so admitted to me that there are times when she thinks the monster has returned."

Because RSD can be re-triggered by injuries, parents often describe, as one father



▲ Allison Switalski, (center) speaks with Rep. Kathy Angerer (right) and local Rep. John Gleason about her rare neurological disease called Reflex Sympathetic Dystrophy.

did, "the tight knot in our stomachs whenever they so much as bump themselves."

Still, they rejoice with each other over each improvement and remission, Dorthy said.

"You'd think it would make you feel bad to hear someone else's good news when you're still suffering. But we don't feel that way. Hearing that someone else is getting better gives us hope."

When Dorthy shared that

Allison had begun walking again, another mother responded, "I have tears in my eyes for you. I know the feeling well. I had that experience just last year when my daughter first walked for the first time in 17 weeks. May your good news continue to grow."

"What fantastic news!" another mom wrote of Allison's remission.

"This gives us hope that RSD can disappear for other

children, too."

One parent in particular has shared the joy of Allison's recovery: Peggy Sivik of Cleveland has a 15-year-old daughter, Mandy, with RSD.

Peggy and Mandy have been an online source of advice, support, prayer and encouragement to Dorthy and Allison. The friendships were deepened when two families met last year in Cleveland.

It was the first time Mandy and Allison met someone near their own ages with RSD, Dorthy said.

"We understood so well what we'd been through, we could finish each other's sentences."

Mandy is in almost constant pain, misses most activities with friends and uses a wheelchair. Still, she "gave a whistle and a hoot" when she recently heard good news about Allison.

With support like that, even the fiercest monster begins to seem smaller.

For more information about RSD help and support groups, call the Reflex Sympathetic Dystrophy Syndrome Association at (877) 662-7737 or visit the group's Web site, www.rsd.org.

Sesame: Fruits, veggies now main source

"We are not putting Cookie on a diet," she says, with a hint of patient exasperation. "We're not taking cookies away from Cookie. It's about teaching moderation."

"We are not about intervention, we are about prevention — putting healthy habits in (kids') daily lives."

For the season that began April 4, "Sesame Street"

decided to target the rampant problem of childhood obesity. So at the top of every show, a "healthy habit" is introduced. There are new characters: singing eggplants and sweet potatoes, talking apples and bananas. Elmo and Zoe play a healthy food game and learn about the benefits of exercise while jumping rope. More than a dozen senators agreed to film "healthy habit" public service announcements with the "Sesame Street" Muppets.

Baby Bear tells a story that involves those singing

vegetables in a wizard's garden. Grover moonlights as an exercise instructor. Miles has a new song: "Broccoli Is Good," sung to the tune of Chuck Berry's "Johnny B. Goode."

And remember, it is for Cookie, the Cookie Monster anthem?

Well, there's a song in town, and it's called "A Cookie Is a Sometime Food."

The parody — this one based on "Porgy and Bess" — "A Woman Is a Sometime Thing" — is sung by Hoots the Owl and a banana, some grapes, a pineapple and an apple.

So Cookie eats his fruit (not the singing ones, of course) enthusiastically. But at the end, he wants his cookies. And gets them.

Well, one.

"That sounds perfectly

reasonable," says Margo Wootton, the Center for Science in the Public Interest. "You can't build a whole diet around cookies!"

Teaching kids about good life habits fits in perfectly with the mission of "Sesame Street."

long considered the hallmark of educational children's programming. So let's just accept it and admit it. This is good for kids. Most parents probably

Elmo can get their 3-year-olds to eat the peas instead of dropping them under the table.

Somehow, though, that doesn't make it easier to accept that Cookie Monster now is tossing salads on the Sesame Workshop Web site. What's next, Scooby-Doo restricted to organic kiwis?

The clink for Count Chocula, Toucan Sam and Cap'n

Crunch?

"Kudos to Cookie Monster for trying new things," says Ronald McDonald in a statement through his corporate office. Ronald understands

Cookie Monster's dilemma. He, too, has undergone such a transformation. Yogurt has made its way onto McDonald's Happy Meal menu. Grilled chicken salads are available for moms. This

January, Ronald was promoted to "Chief Happiness Officer" — which, translated, turns out to be a "character who tells schoolchildren that french fry consumption equals a need for exercise."

"It's great to know you can have your cookies and eat fruit, too," The Ronald said. "It's cool to try different foods and fun to stay active and fit. The way I look at it, it's what I eat and what I do and I'm lovin' it. Let's do lunch!"

Yes, of course, it is all an overreaction.

The world is not coming to an end. Is it a slippery slope? Perhaps. But Oscar the Grouch is not going to go to Zoloff. They swear.

Health briefs

BONE CHECK

Bone density screenings offered at Kroger stores

Bone density screenings will be offered at local Kroger Stores during May for \$15.

Running Nurse Services of Michigan and Kroger developed the partnership to screen for the early signs of osteoporosis, a bone disease that can make bones susceptible to fracture. The bone scan is done of the ankle.

Screenings are planned for: 9 a.m.-1 p.m. Tuesday at Kroger, 3288 Corunna Road, Flint Township; 9 a.m.-1 p.m. Wednesday at Kroger, 2629 W. Pierson Road, Flint; 9 a.m.-1 p.m. Thursday at Kroger, 7188 N. Saginaw St., Mt. Morris; 9 a.m.-1 p.m. May 9 at Kroger, 7084 Miller Road, Swartz Creek; 9 a.m.-1 p.m. May 10 at Kroger, 817 State St., Davison; 9 a.m.-1 p.m. May 13 at Kroger, 1200 E. Bristol Road, Burton; 9 a.m.-1 p.m. May 17 at Kroger, 840 S. Main St., Lapeer; 9 a.m.-1 p.m. May 18 at Kroger, 1542 E. Pierson Road, Flushing; 9 a.m.-1 p.m. May 20 at Kroger, 12731 S. Saginaw St., Grand Blanc; 9 a.m.-1 p.m. May 23 at Kroger, 3838 Richfield Road, Flint and 9 a.m.-1 p.m. May 26 at Kroger, 5249 Corunna Road, Flint Township. Details: Call VNS at (866) 800-0135.

BOTOX BENEFIT

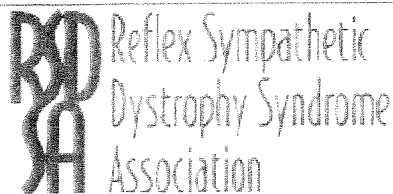
Botox shot proceeds benefit disabled kids

A Botox benefit to raise money for research that might unlock children's mental impairment will be 9 a.m. May 21 at Silverton Skin Institute, 8245 N. Holly Road, Suite 101.

Dr. Kimball Silverton, a board-certified dermatologist, will provide injections of the wrinkle-erasing Botox at a reduced cost. Allergan Inc., the drug maker, is donating the Botox.

For details or to schedule an appointment, call (810) 606-7500.

— Compiled by Shantell M. Kirkendall


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[Related Sites](#)

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About RSD | CRPS > Fact & Fiction

Reflex sympathetic dystrophy syndrome (RSD) is poorly understood by patients, the families, and healthcare professionals. In some cases the condition is mild, in some moderate, and in others it is severe. We have compiled a list of some of the common misconceptions about this syndrome followed by the facts.

Reflex Sympathetic Dystrophy Syndrome (RSD/CRPS) is rare.

FACT — It is not a rare disorder and may affect millions of people in this country. The syndrome occurs after 1 to 2 % of various fractures, after 2 to 5% of peripheral nerve injuries, and 7 to 35% of prospective studies of Colles fracture. The diagnosis is often not made early and some of the very mild cases may resolve with no treatment and others may progress through the stages and become chronic, and often debilitating.

RSD/CRPS is a recently discovered disease.

FACT — It was described during the Civil War and has been in the literature under a variety of names ever since.

RSD/CRPS does not spread.

FACT — The usual pattern of spread is up the same extremity and then may continue to spread on the same side of the body or to the opposite extremity. RSD/CRPS may spread to a distant site. To read an evidence study on RSD/CRPS and spreading, click here.

RSD/CRPS will burn itself out in 6 months.

FACT — Many patients who are not treated early will experience spread of RSD and this may become a lifelong problem. Even with early treatment this may become a chronic condition.

Children do not get RSD/CRPS — limb pain in children is psychological.

FACT — RSD/CRPS can start as young as 3 years of age. This is not a psychological condition. Children may develop psychological problems when physicians, parents, teachers, and other children do not believe their complaints of pain.

Minor injuries cannot cause RSD/CRPS.

FACT — Minor injuries, such as a sprain or a fall are frequent causes of RSD/CRPS. RSD/CRPS can start immediately after the injury or later. One characteristic of RSD/CRPS is that the pain is more severe than expected for the type of injury that occurred. In 10 to 26% of cases no precipitating factor can be found.

A painful limb should be put in a cast.

FACT— Casting and immobilization can cause worsening of RSD/CRPS symptoms. In some cases it may be necessary, but great care should be taken. Although not well studied, available clinical data suggest that immobilizing an injured limb for an extended period may be a risk factor for developing RSD/CRPS.

After one or two treatment programs have not helped, there is nothing that can be done. The patient should be told to go home and learn to live with the pain.

FACT — There are many forms of treatment for RSD/CRPS. Treatment may include medication, sympathetic nerve blocks, physical therapy, psychological support, and possibly sympathectomy, or dorsal column stimulator. The physician directing the care of the patient should have a treatment plan. In severe or long term cases, a Pain Clinic with a coordinated plan may be helpful.

Patients continue to complain because of secondary gains. They are looking for sympathy and are gaining satisfaction from this experience.

FACT — As with any group of individuals there is a small percentage of RSD/CRPS patients who get satisfaction from a chronic illness. The vast majority of RSD/CRPS patients were active, productive individuals prior to this disease and do not enjoy the pain, the loss of independence, the loss of job or inability to attend school and the loss of income. The most devastating aspect of the illness is that physicians, other health care professionals, employers and especially friends and family members do not understand how much the patient is suffering. They are not looking for sympathy, or understanding.

Once RSD/CRPS is in remission, it does not come back.

FACT — It may subside for years and then recur with a new injury. The reoccurrence should be treated immediately.

Vigorous and aggressive physical therapy is best.

FACT — Physical therapy should be carried out only under a physician's supervision. Osteoporosis occurs with RSD/CRPS and as a result of bone loss, pathological fracture can be caused by overly aggressive therapy. Additionally, nerve entrapment and other disorders are sometimes mistakenly diagnosed as RSD/CRPS. Proper diagnosis should be obtained from a competent physician.

Physical therapy should be part of a program of pain control and sympathetic blocks (as indicated). Mobilization of the affected limb is a very important part of treatment and should be carried out by a therapist who is familiar with RSD/CRPS. The goal is to keep the limb moving as much as possible and enable the patient to perform normal activities. In general, "To hurt, is not to harm" as long as the patient is self mobilizing. Aquatic therapy at a comfortable water temperature can often facilitate mobilization of extremities, especially if RSD/CRPS is in the lower extremity.

However, the cliché "No pain, no gain" does not apply to RSD/CRPS patients.

The treatment for all RSD/CRPS patients should be the same.

FACT — Each patient needs an individual treatment plan. What helps one patient, may not help another.

RSD/CRPS is not recognized as a reason for long-term disability.

FACT — It is. The Social Security Administration recently published a ruling on RSD/CRPS. The physician directing the patient's care should write a letter or report describing the severity of the condition and detailing the patient's functional limitations to substantiate the claim. For more information, see the section on Social Security in our Resource Directory for patients with RSD.

Any physician can treat RSD/CRPS without outside help.

FACT — RSD/CRPS is a complex condition with varying degrees of severity and disability. Patients should be cared for by a physician who knows how to treat RSD/CRPS. Often, a team approach (physician, physical therapist, anesthesiologist, mental health provider, and social worker) is most helpful.

There are no symptoms except pain, swelling, heat or coldness, and color change.

FACT — There are many other symptoms including movement disorders (difficulty starting movement, increased tone, increased reflexes, tremor, muscle spasms), weakness, fatigue, skin rashes, frequent infections, migraine headaches, and others may be found as more data is accumulated.

Family and friends find this condition easy to understand.

FACT — RSD/CRPS is difficult for many physicians to understand. It is not surprising that family and friends do not understand the patient's pain and disability.

The pain is not as bad as the patient says it is.

FACT — The pain is often as bad as claimed and may be even worse.

Blocks and other treatments only work in the first stage of the disease.

FACT — There are treatments that will help in any stage of RSD/CRPS. If RSD/CRPS spreads or if a new injury occurs, blocks may be effective again.

Narcotics do not help relieve the pain.

FACT — Narcotic medications are effective in some patients with RSD/CRPS. This is always a controversial issue. They are used when non-narcotic pain relievers are not effective and are used to reduce the level of pain until other forms of therapy become effective. A formal written contract-protocol between the patient and physician can help minimize misunderstandings about the potential complications of narcotic use.

RSD/CRPS occurs in psychologically unbalanced people.

FACT — Persons who get RSD/CRPS are not any different than the rest of the population psychologically. Once they get RSD/CRPS and they are in constant pain they may be depressed and suffer other psychological changes. When RSD/CRPS symptoms are relieved these changes disappear.

Every patient has the same results from a medication or treatment.

FACT — There are many forms of treatment and combinations of treatment and medication. What is highly effective for one, may not work in another. Medication dosages may need to be adjusted to get the best results.

A patient who has no visible sign or positive tests does not have RSD/CRPS

FACT — RSD/CRPS is a clinical diagnosis. This means that the physician makes the diagnosis based on thorough history and physical examination. When seeing a new physician, it is a good idea to have a brief medical history with dates of various treatments and the response to them. Also include a brief summary of any hospitalizations and surgeries. It is helpful for the doctor to have a copy of this information before your appointment. Given the complexity of RSD/CRPS, it is helpful for the patient to keep their own set of relevant medical records.

RSD/CRPS does not occur in families.

FACT — As we are accumulating data we are finding families with two or more members with RSD/CRPS. This is true in about 5% of the cases.

RSD/CRPS following surgery means that the physician did something wrong

FACT — RSD/CRPS can occur following surgery as well as a trauma. This does not mean that the surgery was performed incorrectly.

There is no hope for patients who have had RSD/CRPS for a long time.

FACT — The future of RSD/CRPS treatment is optimistic. Researchers worldwide investigate effective treatments and the cause of RSD/CRPS.

We hope all physicians will recognize and diagnose RSD/CRPS in the early stages so that the patient can be treated promptly and appropriately. Any physician unfamiliar with the treatment of RSD/CRPS should refer patients immediately to a physician or center that treats RSD/CRPS.

Updated 8/2/2005

On the scale RSDS/CRPS is represented by the word CAUSALGIA

They are the one in the same

